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# Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES



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## About ICES

ICES is an independent, non-profit research institute. As a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use healthcare data for the purposes of health system analysis, evaluation and decision support. Secure access to these data is governed by policies and procedures that are approved by the Information and Privacy Commissioner of Ontario. ICES research provides measures of health system performance, a clearer understanding of the shifting healthcare needs of Ontarians and a stimulus for discussion of practical solutions to optimize scarce resources.

## The ICES Peoples' Panel

The Peoples' Panel was convened to guide ICES' approach on the use of **race, ethnicity** and immigration data at an institutional level. Individuals from across Ontario who identified as **racialized** or who had an interest in how race data are used were recruited through an open call. No experience in health, science or policy was needed. We sincerely thank the members of the ICES Peoples' Panel and the Tamarack Institute and Digital Justice Lab for their contributions to this Document. To access the full Peoples' Panel Report, see [Appendix 2](#).

## Acknowledgements

This Document was supported by ICES, which is funded by the Ontario Ministry of Health (MOH) and Ministry of Long-Term Care (MLTC). The opinions, results and conclusions are those of the authors and are independent from the funding source. No endorsement by ICES, the MOH or the MLTC is intended or should be inferred.

In March 2023, targeted consultations were undertaken with 13 community representations and equity experts to discuss community-led data governance. These consultations provided detailed recommendations on how to plan for community-led governance of race and related data at ICES, which will be used to guide this work moving forward. We thank those who provided their time and expertise for these discussions.

## Peer Review

ICES conducted several rounds of peer review during the development of this Document. We sincerely thank the following groups for their review:

**The ICES Internal Committee of Scientists ([Appendix 3](#))**  
**The ICES [Scientific Advisory Committee](#)**  
**ICES Program Leaders and Site Directors**  
**ICES Staff, Scientists and Trainees**



# Table of Contents



Executive Summary	11
About this Document	26
Background	34
Goals of This Document	42
Community-Informed Principles for Appropriate Use of Race and Related Data	46
<b>Framework to Drive Anti-Racist Approaches to Health Research at ICES</b>	58
<b>Domain 1:</b> Anti-Racist Research	60
<b>Domain 2:</b> Community Access	68
<b>Domain 3:</b> Community Governance	74
<b>Domain 4:</b> Accountability for Impact	80
Implementation: Our Commitment to Action	86
Implementation Plan: Practice Profile Methodology	90
<b>References</b>	98
<b>Appendix 1:</b> Internal Guidance Memo	102
<b>Appendix 2:</b> Peoples' Panel Report	105
<b>Appendix 3:</b> The Guidance Document Development Process	106
<b>Appendix 4:</b> Glossary of Terms	112

...collecting and using race and related data responsibly for health system improvement has been highlighted by communities, human rights advocates, equity researchers and other groups...



## Executive Summary

The importance of collecting and using race and related data responsibly for health system improvement has been highlighted by communities, human rights advocates, equity researchers and other groups advocating for anti-racist research. To address these calls to action, ICES consulted with members of the public, external health equity experts, as well as internal staff, scientists and senior leaders to develop a **Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics**.

The aims of this Guidance Document and Framework are to outline organizational strategies to help implement anti-racist and anti-oppressive practices, support appropriate use of race and related data at ICES, prompt scientists and research teams to consider the role of systemic racism and other forms of oppression in perpetuating health inequities and support communities to access impactful research that is responsive to their needs and priorities.

### Note on use of the term “race and related data”

The term “race and related data” refers to any data held at ICES that can identify or infer race, including race, ethnicity, or mother tongue. Certain immigration variables are also included under this umbrella term (e.g., country of origin).

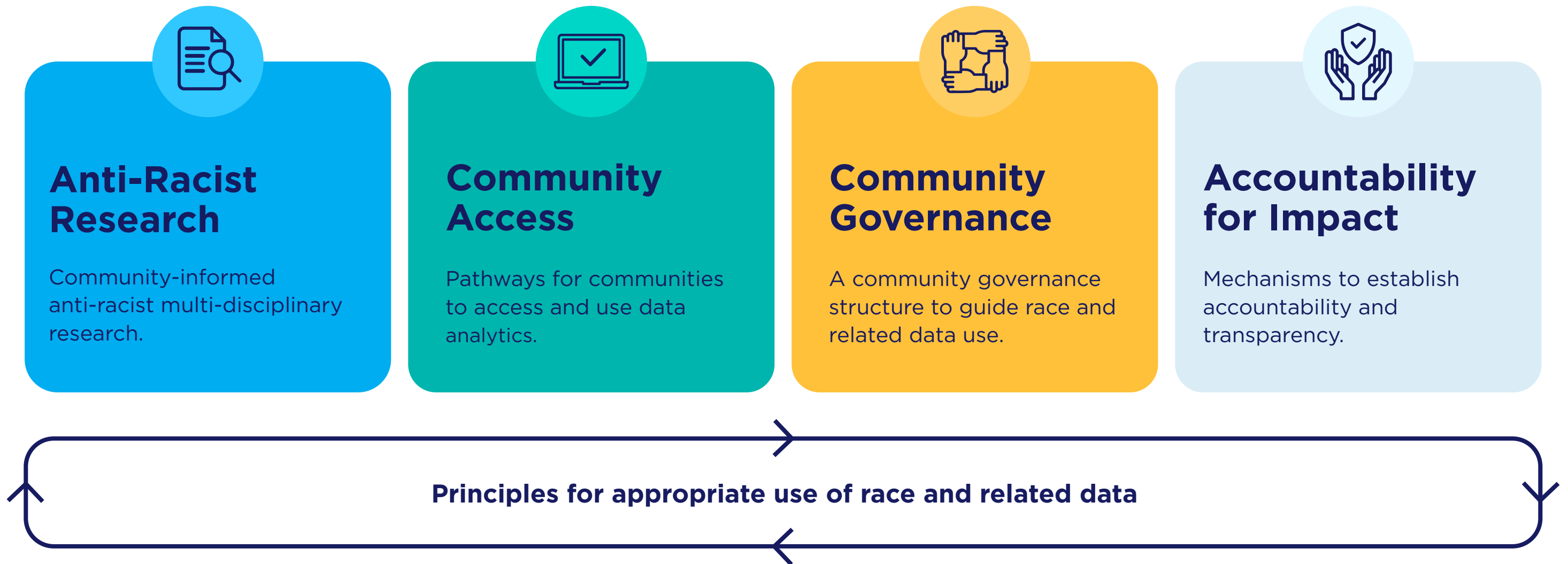
### Note on Indigenous identifiers and data

ICES has previously developed distinct approaches and policies for Indigenous data governance in partnership with Indigenous leadership organizations. The Framework below was informed in part by the [ICES Indigenous Data Governance Principles Framework](#), which was initially developed in collaboration with the [Chiefs of Ontario](#) and the ICES Indigenous Portfolio for First Nations data and research. Given the distinct approach of the ICES Indigenous Portfolio work, this Document does not discuss Indigenous identity or data. More information for ICES Scientists on using Indigenous data can be found on the [intranet](#).



# Framework to Drive Anti-Racist Approaches to Health Research at ICES\*

The *Framework to Drive Anti-Racist Approaches to Health Research at ICES* (The Framework) is organized into four domains. Each domain includes a goal and components that guide ICES' commitment to racial equity in health research. At the foundation of the Framework are the principles for appropriate use of race and related data informed by the Peoples' Panel, a group of over 50 members of the public, which underpin the four core Framework domains.



\* The Framework to Drive Anti-Racist Approaches to Health Research at ICES was informed in part by the [ICES Indigenous Data Governance Principles Framework](#), which was developed in collaboration with the [Chiefs of Ontario](#) and the ICES Indigenous Portfolio. The ICES Indigenous Data Governance Principles Framework is a data stewardship model, where Indigenous data are held at ICES but governed by appropriate Indigenous organizations/communities.



# Principles for Appropriate Use of Race and Related Data

These overarching principles were established as the foundation of The Framework

## We will...

**1** Report biases/limitations and engage with equity scholars across many disciplines and communities for appropriate research conduct and contextualization.

**2** Discuss racism and evaluate the impact of health policy on racialized populations.

**3** Be explicit about the reasons for using race and related data in research and vet research practices with representative community members and health equity experts.

**4** Use race and related data to illustrate the impact of racism on health and advance health equity.

**5** Engage communities in a respectful way to collaborate on how data are used, interpreted and shared as well as fund research analytics for community-identified needs.

**6** Clearly define study limitations and collaborate across disciplines to contextualize studies that use race and related data.

**7** Acknowledge that “race” and “ethnicity” are different concepts with no fixed definitions and do not represent genetically distinct homogeneous groups.

**8** Integrate self-reflection and positionality throughout the research process.

**9** Contextualize research findings by exploring systemic racism and its broader influences on other social and structural determinants of health.

**10** Consider the interaction of important social determinants of health such as poverty and education as well as how various forms of discrimination such as racism, sexism and ableism overlap.



## DOMAIN 1

# Anti-Racist Research



## Goal:

Promote community-driven and community-informed anti-racist and multidisciplinary research at ICES.

## Domain Components

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### 1.1 Internal Capacity-Building and Community Engagement

Provide education and resources on health equity through tangible tools and consultations with the Public Engagement and Knowledge Translation (PEKT) team. Support research teams with tools and training on planning and conducting meaningful community engagement in an ICES project, including dissemination of results back to community members whose data have been included.

### 1.2 Broadening Expertise

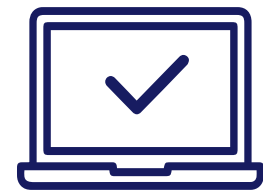
Foster interdisciplinary partnerships and engagement with equity scholars to broaden the science in health equity and promote internal capacity. Provide non-ICES scientists accessing data through Data and Analytic Services (DAS) the same guidance on appropriate use of race and related data at ICES.

### 1.3 Data Quality Assessment and Data Acquisition

Assess the data quality and controls currently in place through a review and report of the source and validity of race and related variables/algorithms within the ICES repository. Assess the quality and collection of newly acquired data for the ICES repository.

## DOMAIN 2

# Community Access

**Goal:**

Create pathways for communities and organizations serving racialized communities to access and use data analytics through the Applied Health Research Question (AHRQ) Program.

**Domain Components****2.1 Community Awareness and Accessibility**

Use targeted strategies to increase community awareness of pathways to access race and related data analytics through the AHRQ program. Explore additional funding opportunities to support community-driven AHRQs and ensure appropriate resource allocation for projects with a health equity focus.

**2.2 Mutual Capacity-Building**

Support knowledge users of community-driven AHRQs with context to use race and related data for the purpose of effective knowledge translation to communities they serve. Reciprocally engage in learning with communities on contextualization of their data.

DOMAIN 3

# Community Governance



## Goal:

Co-design and implement a community-led governance structure at ICES to guide corporate and project-level initiatives involving race and related data.

## Domain Components

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### 3.1 Community Governance Structure

Co-design a community governance structure at ICES through consultation with community representatives and develop a mandate that outlines the purpose and goals of this work. Establish a community governance advisory table under this structure to provide corporate and project-level guidance.

## DOMAIN 4

# Accountability for Impact



## Goal:

Create and implement mechanisms to ensure accountability and transparency when using race and related data.

## Domain Components

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### 4.1 Knowledge Mobilization

Communicate key findings from ICES research using race and related data clearly and directly to impacted communities. Create opportunities for information sharing and mutual engagement.

### 4.2 Transparency

Monitor research activities using race and related data to transparently report progress toward meeting the committed actions of the Guidance Document. Establish mechanisms to quantify metrics related to race and related data access and use at project initiation and publication.

### 4.3 Reporting Mechanisms

Establish reporting mechanisms for community organizations conducting an AHRQ project to provide ongoing feedback on how the process can be improved for accessibility and equity.



**This Document is not prescriptive in how scientists should analyze race and related data, but rather is one step in a larger process...**



## Concluding Remarks

The Guidance Document and Framework outline the key actions ICES is taking toward establishing an anti-racist research agenda and appropriate use of race and related data across the organization. This Document is not prescriptive in how scientists should analyze race and related data, but rather is one step in a larger process to improve data use practice and encourage reflection on how racial health inequities result from social determinants rather than biological differences. The shift from “race” to “racism” is one that will look different in each ICES project.

For questions on the Guidance Document and Framework, we encourage you to connect with the ICES Public Engagement and Knowledge Translation Office ([public@ices.on.ca](mailto:public@ices.on.ca)) to discuss how we can assist you.



# About this Document



ICES is an independent, not-for-profit research institute made up of a community of research, data, clinical and health system experts working in a seven-site network across Ontario. Our mission is to translate data into trusted evidence that improves policy and healthcare and makes people healthier. ICES provides scientists with secure access to health-related data for Ontario's population, including population-based health surveys, de-identified patient records and administrative and clinical databases. The ICES strategic plan has explicitly listed health equity as a priority since 2020.<sup>1</sup>

# The disproportionate impact of the COVID-19 pandemic on racialized communities has renewed focus on the need for race and ethnicity data in Ontario.



## Preface

Racial health inequities have been well documented in Canada and internationally, with **racialized** groups experiencing poorer health, limited access to healthcare and overall worse health outcomes that were further exacerbated by the COVID-19 pandemic.<sup>2-4</sup> The disproportionate impact of the COVID-19 pandemic on racialized communities has renewed focus on the need for race and ethnicity data in Ontario and more widely in Canada for health system improvement and improving the health of all Canadians. With this renewed focus, the importance of collecting and using **race** and **ethnicity** data responsibly has been highlighted by communities, human rights advocates, equity researchers and groups advocating for an anti-racist approach. An effort to collect race, ethnicity and household income variables for those who tested positive for COVID-19 was led by a few public health units, and the practice became provincial in scope by June 26, 2020. The Ontario Ministry of Health (MOH) also expedited COVID-19 data transfers to ICES to provide real-time data on COVID-19 testing, infections and vaccine uptake in Ontario. Many of the resulting ICES COVID-19 reports were used by public health units to provide the community organizations with whom they work a detailed look into the gaps and issues impacting their community's health.

For the past three decades, the ICES community has generated high-quality, rigorous research that endeavored to improve health outcomes both for Ontarians and more widely. Since ICES' inception, some projects have focused on health inequities, but, while ICES holds multiple linked demographic **data holdings**, many important social determinants of health are not well captured in existing data. In addition, there have been relatively few projects that have engaged directly with communities or community organizations. To facilitate high-quality research for the health of all Ontarians, ICES is developing key policies and processes to govern data access relating to race and ethnicity data. Specifically, with increased interest in collecting more data on social determinants of health and proposed legislative changes in Ontario that will allow ICES to collect and use data from other ministries, data on race, ethnicity and other factors must be governed, used and collected responsibly. The communities represented in the data should be engaged in these processes and resulting analyses should be reported back to the communities who are directly impacted.





To address this need, ICES has developed explicit guidance on an approach to anti-racist and community-driven health research and analytics at ICES. Through this Guidance Document, we aim to ensure that the use of **race and related data** held at ICES can help reduce health inequities including by demonstrating the role of **systemic racism** and other forms of **oppression**. We acknowledge that communities are best positioned to understand their needs and the specific contexts that contribute to health inequities. As such, we aim to support community efforts to examine and address the social determinants of health, dismantle root causes of inequities and conduct impactful and responsive research based on their needs and priorities, all with the aim of increasing health equity through the responsible use of data. This Guidance Document will help our scientists, staff and trainees to understand the direction ICES is taking toward anti-racist and anti-oppressive practices. In addition, many research groups, institutions and external scientists in the health research sector either leverage

ICES data through Data Analytics Services (DAS) or the Applied Health Research Question (AHRQ) program. This Document will also apply to those data users, and will be used to share our approach, policies and processes with external scientists, data partners and community organizations to increase awareness of and promote further work in this area. ICES recognizes that this Document will evolve over time and will be updated accordingly as terminology and best practices change, and in ongoing dialogue with relevant communities. The Document is intended to be iterative.





### Note on the use of the term “racialized” (group or person)

The term “racialized” is used throughout this Document to denote groups and people who experience **racism**. A common misconception is that the term “racialized” characteristically refers to anyone who is not “White.” Our intent is to convey that “racialization” is something imposed by society on certain groups as a result of **systemic racism** and is not intrinsic or inherent. Racialized people can be impacted by antisemitism and Islamophobia among other forms of racism and discrimination, and experience substantial socioeconomic, health and societal impacts.<sup>5</sup>

### Note on use of the term “race and related data”

The term “race and related data” is used to abbreviate the text throughout this Document. It refers to any data held at ICES that can identify or infer race, including **race, ethnicity** or mother tongue. Certain immigration variables, such as country of origin, are also included under this umbrella term. Race is a term used to classify people into groups based principally on physical traits (i.e., phenotypes) such as skin colour.<sup>5</sup> Racial categories are not based on science or biology, but rather they are **socially constructed** with significant consequences for people’s lives. Racial categories should be self-identified, may vary over time and place and can overlap with ethnic, cultural or religious groupings. It is important to note that the variable of **race**, especially when it is socially-assigned (i.e., imposed on a person by others) is often used as a proxy for what is truly being measured: exposure to **racism**.

### Note on Indigenous identifiers and Indigenous data

For several years, ICES has worked closely with Indigenous (First Nations, Inuit and Métis [FNIM]) partners to develop unique data governance. ICES has developed distinct approaches and policies for Indigenous data governance in partnership with Indigenous leadership organizations, and we currently work directly with Indigenous partners to ensure appropriate data use. The work with FNIM partners in data governance at ICES has laid the groundwork and highlighted the importance of establishing community-led governance of race and related data. ICES currently has governance agreements in place with First Nations and Métis organizations. For example, ICES and the Chiefs of Ontario (COO) signed a Data Governance Agreement in 2012, and the COO established a First Nations Data Governance Committee that receives

and approves proposals for the use of the Indian Registry System and Ontario-level analyses involving other First Nations identifiers. ICES and the Métis Nation of Ontario (MNO) also signed a Data Governance and Data Sharing Agreement and developed a joint Data Governance and Partnership Committee in 2016. The Committee reviews requests for the use of linked MNO data at ICES and acts as a consultative body for projects involving the self-identified Métis population.

Historically, Indigenous people have not been consulted on data collected about them and how that data has been used, which has resulted in years of harm and misuse of data.<sup>6</sup> The First Nations principles of OCAP® (ownership, control, access, and possession) asserts that First Nations own their information and that they are stewards of their data.<sup>6</sup> The First Nations Principles of OCAP® are closely followed in the use of different types of data that identify First Nations people and communities in ICES’ data holdings.<sup>6</sup> Ultimately, these principles and approaches were critical in informing this Guidance Document and Framework, but, given their distinct approach, this Document will intentionally not discuss Indigenous identity or data with Indigenous identifiers. More information on Indigenous data at ICES can be found on the ICES [Indigenous Portfolio webpage](#).

### Note on use of the terms “community” and “communities”

Throughout this Document, the terms “community” and “communities” are used to define populations of individuals who have historically been excluded from health research, stigmatized or harmed as a result of research findings and denied access and control of their data. These communities represent many **marginalized** groups and this term is not meant to relate to geographically defined areas. Defining communities based on **race** and **ethnicity** alone is not straightforward and represents neither diversity nor **intersectionality** of identities. We use the terms “community” and “communities” in an effort to acknowledge all potential groups who should be meaningfully engaged when their data are included in a study, understanding that it can be challenging to ensure representative voices are included at the table. ICES scientists should carefully consider who is included within their study data, the health/health service outcome of interest, and, where possible, consult with relevant community representatives to identify who should be included and how to engage them in the work.

### Glossary:

For a full list of key concepts and definitions used throughout this Document, see the [Glossary of Terms](#) (Appendix 4).



# Background







The historical and contemporary use of **race** in medicine and health research is inseparable from **racism**.<sup>7,8</sup> Racism is defined as “the ideas and practices that establish, maintain, or perpetuate racial superiority or dominance of one group over another.”<sup>5</sup> Medical training and health research has, until very recently, often implied that racial group health disparities are the result of inherent biological or genetic differences. However, population geneticists have long known that health disparities between racial categories are not genetically determined and repeatedly cite robust evidence that racial groups are genetically heterogenous, with more variation within any racial group than between groups.<sup>9-11</sup> On the other hand, geneticists acknowledge that **ancestral** groups, which are racially heterogenous and best delineated by large geographic boundaries, are genetically similar and experience similar risks for some health outcomes. An example of this is sickle cell disease which is often described as a disease experienced by Black people (i.e., Africans and African Americans), but, in fact, the sickle cell gene is also common among populations residing in parts of India, the Middle East and the Mediterranean.<sup>12,13</sup>

By contrast, other disciplines (e.g., anthropology, history, sociology) have understood that race is **socially constructed** (i.e., an idea invented by people) and based principally on physical traits such as skin colour and hair texture and has no scientific basis.<sup>13-18</sup> American sociologist Dorothy Roberts further describes race as a “political division and a system of governing people that classifies them into a social hierarchy.”<sup>16</sup> This social (i.e., racial) hierarchy has and continues to be used to justify the subjugation and exploitation of Indigenous, Black and other **racialized** people by mainly White European populations, and other dominant populations, around the world. This understanding of race has finally begun to gain widespread acceptance in the medical research community following the police killing of George Floyd in the US in May 2020, further amplified by the disproportionate burden of SARS-CoV-2 and COVID-19 related outcomes among racialized persons in the US, Canada and globally, and brought to light by the tireless dedication of clinicians and researchers with lived experience of racism and an understanding of the harmful history of race in medicine.<sup>19-23</sup> Over the last few years, numerous prominent medical journals have acknowledged medical research’s complicity in justifying racist ideology (e.g., the origins of craniology<sup>24</sup> and gynecology<sup>25</sup>), which has supported and reinforced the racial hierarchy.<sup>26-29</sup> Many of these journals also have acknowledged that racial differences in health are historically rooted in **eugenics**, **colonialism** and **white supremacy**. When explaining the causes of racial health inequities, a shift from the false focus on natural, immutable difference to that of powerful social and political forces (i.e., a re-focus from **race** to **racism**) is critical, as this will assist the medical and health research community to confront racism as a human-made system and to mobilize knowledge and resources to eliminate racial health disparities more effectively.<sup>30</sup>







### ICES' Position Statement on Racism and the Use of Race and Related Data

Historically, there has been a lack of data and reporting on **racism** in health and healthcare in Canada. Community members, human rights advocates, equity researchers and groups advocating for an anti-racist approach have called for more robust data collection and analysis to better demonstrate pervasive inequities experienced by racialized people. Not all agree that more data collection or descriptions of disparities will truly benefit communities which have been historically **marginalized**, and it is important to acknowledge the potential for ongoing harm that can occur through approaches that further “bake in” discrimination (e.g., kidney function algorithms that adjust for race).<sup>31</sup> It is also critical that scientists carefully consider their use of **race and related data** and the groups who will benefit as a result. Research that emphasizes differences between groups can inadvertently lead to victim-blaming rather than dismantling the **systemic racism** that often benefits White communities. For example, studies focusing on disparities between White and Black men often approach the findings from a “problem” space, highlighting the substantial differences in social or health related outcomes that exist for Black men. Rarely do we see research from a “solution” space that addresses ways to minimize practices that perpetuate these inequities.<sup>31</sup>

In Ontario, the Black Health Equity Working Group released the Engagement, Governance, Access, and Protection (EGAP) framework, which describes governance structures needed for the collection, management, analysis and use of data from Black communities.<sup>32</sup> The

EGAP framework emphasizes the importance and current lack of appropriate data, analytics, community governance and community engagement by government and research institutes who use data from Black communities. The creation of this Document to guide appropriate use of race and related data was in part to address the EGAP recommendations and the call for research institutes to improve data collection, use and governance. ICES acknowledges that recommendations within the EGAP have not previously been taken up, and efforts must be made moving forward to ensure all race and related data are used and governed responsibly. ICES also acknowledges its own historical contributions to potential harm and inequities, perpetuated through limited controls and guidance for scientists using race and related data. As a steward of health data, ICES encourages the use of race and related data to address health inequities in research when done so in a way that both reflects the values and perspectives of communities directly impacted and acknowledges the benefits that systemic racism has afforded to White communities. It is our organizational responsibility to ensure that, moving forward, we affirm our stance that systemic racism exists and has direct impacts on our health systems. Although ICES does not directly influence the research questions that are asked by our scientists, we are in a position to influence the data controls in place, the training and guidance provided and the organizational values upheld for all ICES research.





### Community Call to Action

Calls to action similar to that of the EGAP have further fueled peer-reviewed journals to develop guidelines and enforce more rigorous standards for publishing on racial health inequities, including explicit guidance on data standards, reporting and more direct recognition of **racism** and racial disparities.<sup>19,26,33</sup> There is also increased recognition that racial categories do not represent genetically or biologically distinct homogeneous groups and are not an appropriate proxy for ancestry. It is critical to distinguish between **race** and **ancestry** and how the latter can in some cases more accurately explain certain disease risks in populations.

Within the administrative databases held at ICES, there are currently limited data on race, race-related variables and socioeconomic measures, although these are more prominent in surveys like the Ontario Health Survey or Canadian Community Health Survey. Immigration data can be accessed in the Ontario portion of Immigration, Refugees and Citizenship Canada (IRCC)'s Permanent Resident Database. The IRCC data include immigration application records for people who initially applied to land in Ontario and currently contain permanent residents' demographic information such as country of citizenship, level of education, marital status, English/French language ability and immigration category. However, these data have the potential to stigmatize or harm identified communities if used inappropriately. For example, when country of citizenship data are used to infer race without further explanation or contextualization, substantial misclassification can occur.

Self-reported race data (i.e., individuals identifying their own race) is generally considered the gold standard.<sup>32</sup> This respects individuals' lived experiences and acknowledges that self-identity can change over time and across contexts.<sup>34,35</sup> However, there may also be situations where socially-assigned race (i.e., race classification imposed on a person by others) offers value: it can be an appropriate proxy for experiences of racial discrimination (e.g., differential treatment by care providers).<sup>32,35-40</sup> If available, using multiple dimensions of race (e.g., both self-reported and socially-assigned) in conjunction may aid in nuanced examination of the effects of racism.<sup>35</sup> In other contexts, socially-assigned or algorithmically-derived race data (used pragmatically due to the limited availability of self-reported data) should be applied with caution, and limitations should be recognized.<sup>41,42</sup>

Community members have also identified the importance of **intersectionality** in understanding the far-reaching impacts of systemic racism in healthcare and have called for it to be addressed more directly in research. While intersectionality was originally a legal framework used to explain the **oppression** of African-American women, this concept is now used broadly to describe how identities related to race, ethnicity, gender identity, age, ability, socioeconomic status and other factors can intersect to create complex inequities that are often overlooked in discussions of race and ethnicity.<sup>43</sup> Data to understand the intersections of identity, racism and other forms of oppression are currently not available within the repositories at ICES and often require other data collection methods (e.g., survey data). However, ICES acknowledges that research using a **health equity** lens must expand beyond race and racism alone. The intersection of race with sex, gender, sexual orientation, ability, socioeconomic status and other identities requires thoughtful and meaningful reflection in research and policy, particularly to understand how intersections of identity compound existing structural inequities. ICES has data holdings that include variables for sex, which can be used to study gendered experiences, and census data that provide area-level information on education, income and other measures of socioeconomic status. Detailed guidance will be necessary to ensure that these data are also used appropriately and contextually with race and related data and that communities are engaged when necessary to inform population-based findings. ICES commits to providing guidance in the future and considering new ways to continually build capacity in health equity research across the organization moving forward.



# Goals of this Document



ICES recognizes the global and national impact of **colonialism** and the role of data in decolonizing health research. We are working to build capacity within the ICES research community to increase understanding of the history and complexities of **race and related data** and to support communities in using these data to drive change and address **systemic racism**. We aim to understand our role as a health data research organization in advancing an anti-racist science agenda and leveraging our capacity to provide data to address the systemic racism that impacts health outcomes for many communities.

To conduct this work, ICES convened a Core Working Group to develop and implement guidance for the use of race and related data with support from a wider Internal Committee to help govern approaches and implementation. The resulting Guidance Document was informed by consultation with members of the public (ICES Peoples' Panel), health equity experts as well as ICES' staff, scientists and Scientific Advisory Committee. Additional oversight was provided by ICES' Board of Directors, senior leadership and executives. Further information on collaborators and the development process can be found in [Appendix 3](#).

# Goals of this Document

1

## Guide appropriate use of race and related data

Identify and establish community-driven, anti-racist practices in the use of **race, ethnicity** and immigration data at ICES.

2

## Promote community-driven research

Increase community awareness of opportunities to access and use ICES data analytics to understand and inform action on health inequities.

3

## Sustain anti-racist research with meaningful community engagement

Incorporate practices that support: community-informed and **anti-racist research**, including ongoing capacity-building initiatives to promote understanding of **health equity** in research; appropriate use of race, ethnicity and immigration data; and meaningful engagement with communities, equity scholars and scientists.

4

## Develop community-led data governance

Establish a process for community governance of race, ethnicity and immigration data that represents the voices of communities.

5

## Ensure accountability and transparency

Create sustainable mechanisms for monitoring accountability to community organizations, the public and key stakeholders on equity-driven use of race, ethnicity and immigration data.

## Community-Informed Principles for Appropriate Use of Race and Related Data

As a foundation for this Document, overarching principles to guide the ethical and appropriate conduct of studies using **race and related data** were established. In Spring 2021, ICES worked with the Tamarack Institute and Digital Justice Lab to lead a Peoples' Panel composed of a diverse group of 54 members of the public to advise ICES on approaches to using race and related data for health research. Several of ICES' Public Advisory Council members also participated in the Peoples' Panel. The Peoples' Panel met over five weeks and shared their perspectives on what matters most about the use of these data in research. They commented on the initial overarching principles drafted by the Core Working Group based on a literature review and produced recommendations for specific scenarios on how these data should be used by ICES scientists to better support communities, reduce health inequities and avoid perpetuating **racism** or anti-immigration sentiments. The result of the Peoples' Panel work was a set of principles and recommendations that contributed to the actions included within this Document and ultimately formed the basis for the Framework (subsequently described) to drive racial equity in health research at ICES. The Internal Committee also reviewed these outputs, and leaders at ICES provided a final review and sign-off for the organization. A complete summary of the Peoples' Panel work is outlined in the group's final report ([Appendix 2](#)).

### Key principles and example application

The key principles that emerged from the Peoples' Panel were arranged according to ICES' values to demonstrate alignment with the organizational standards currently upheld. We have also included specific examples of how these principles could be applied in ICES research. Many of these examples are supported by the Canadian Medical Association Journal's *Guidance on the reporting of race and ethnicity in research articles*,<sup>42</sup> as well as advice from the Peoples' Panel and Internal Committee.



# We Strive for Excellence.

Demonstrated by the quality, value, innovation and rigour of our work.

1

When conducting research using race and related data, scientists and project teams will be rigorous in understanding and reporting how biases and limitations shape data collection, analysis and reporting. Engagement with equity scholars across many disciplines and communities is critical for appropriate conduct and contextualization of this research.

## Example guidance for application

- ① In a manuscript or report, describe the data holding(s) and variable(s) used to determine race and how the data were collected (e.g., self-reported on a survey, socially-assigned by clinician report, algorithmically-derived etc.).<sup>42</sup>
- ① When describing the data holdings and variables that were used to determine race and related data in a manuscript, describe any potential biases related to how the data were collected. Be transparent about the limitations of the data, especially if an algorithm was used to derive race.
- ① Include or consult equity scholars and/or community representatives throughout the research process or at key junctures (e.g., proposal writing, outcome prioritization, data interpretation) to safeguard against unintended biases during the research process and to appropriately contextualize findings on race and related data.<sup>42</sup>

# We Behave with Integrity.

Expressed through independence,  
transparency and impartiality.



2

Scientists and project teams have an opportunity and a responsibility to discuss racism in their research, even when related constructs may not be explicitly measured, and to evaluate the impact of health policy on racialized populations when appropriate and possible.

3

Scientists and project teams will be explicit about the reasons for using race and related data in their research, reflecting on their own biases and on how systems have historically benefited White individuals. The way racial or ethnic categories are compared in research should be informed by best practices, including exploring whether within-group differences exist when data is disaggregated, rather than solely reporting between-group comparisons. This practice can avoid oversimplification of the relationship between race and other variables. Ideally, racial categories should also be informed through consultation with representative community members and health equity experts.<sup>19,44</sup>

4

Scientists and project teams will use race and related data in health research to illustrate the impact of racism on health, advance health equity or evaluate solutions to improve the health of the groups or communities represented in these data.

## Example guidance for application

- ① Incorporate data related to the social determinants of health alongside **race, ethnicity** and immigration data to provide context on the role of systemic inequities and/or **systemic racism** in your project. When writing the results, even if **race and related data** were not included, consider how other variables (e.g., income) could be influenced by structures and systems that have historically **marginalized** some groups.<sup>42</sup>
- ① In a table of baseline cohort characteristics, avoid grouping multiple race categories together unless justification is included. Avoid comparing groups to a majority (e.g., White), especially on data visualizations.<sup>42</sup> Refer to the CIHI Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada for appropriate race categories if collecting primary data and importing to ICES.<sup>45</sup>

# We Collaborate.

Through effective partnerships, accessible data and a spirit of openness.



5

Race and related data can be used to drive change. When appropriate, scientists and project teams using race and related data as a key component of their cohort identification will engage communities in a meaningful and respectful way to collaborate on how the research is framed, what questions are asked and how data are used, interpreted and shared.

6

Scientists and project teams will provide clear definitions and limitations of the use of data on race or related concepts. Scientists and project teams should strive to collaborate across disciplines to gain expertise from qualitative research, social epidemiology, sociology, political science and related disciplines to contextualize studies that use race and related data.

## Example guidance for application

- ⑦ From the onset of a study, incorporate meaningful engagement with members of the community who represent the races and ethnicities identified in your cohort. This could be throughout the research process (integrated knowledge translation), at a certain project juncture (e.g., data interpretation), or at the dissemination stage (end-of-grant knowledge translation). The [ICES Public Engagement and Knowledge Translation office](#) can provide support and tools to help plan your engagement(s).
- ⑦ When applying for grants, consider resources and budget needed for effective engagement, including staff time for coordination, appropriate compensation for community participants, travel/transport reimbursement and other areas. Also consider opportunities for collaborating with interdisciplinary experts in health equity outside of ICES.
- ⑦ Consider leveraging relationships and partnerships within ICES and your home institutions to identify community advisors.
- ⑦ Describe your community engagement plan within publications and reports. Involve your community partners in manuscript writing and review.

# We are Respectful.

Exemplified by inclusiveness and appreciation of each other, trust in data stewardship, meaningful public engagement and alignment with Ontarians' values and accountability for our funding.

7

When conducting studies using race variables, scientists and project teams will acknowledge that “**race**” and “**ethnicity**” are different concepts with no fixed definitions. The meaning of racial or ethnic categories reported can change depending on location, time, context of data and from person-to-person. Race and ethnicity categories do not represent genetically or biologically distinct homogeneous groups and are not an appropriate proxy for **ancestry**.

8

ICES will provide resources to support scientists and project teams to incorporate best practices in acknowledging the potential influence of positions of privilege and personal biases to the interpretation of race and related data. This self-reflection and positionality of the research team should be integrated throughout the research process and will be supported by resources available to scientists and project teams at ICES.

## Example guidance for application

- ⑦ Within your project, race and related data should **not** be used as a surrogate for biological or genetic ancestry. In most cases, higher risk/prevalence of adverse health outcomes should not be equated with biological or genetic predisposition or used to demonstrate inferiorities of one or more racial groups. If there are exceptions to this rule (e.g., the association between skin pigmentation and vitamin D levels) the validity of using race and related data must be clearly acknowledged and justified.<sup>42</sup>
- ⑦ Avoid using terms that imply a hierarchy or othering (e.g., “non-White”, “non-Immigrant”). Terms such as “underserved,” “equity-deserving,” “equity-denied,” or “historically marginalized” (which more accurately imply a deficit in systems of privilege rather than in the groups themselves) can be used, accompanied by a definition of who is included in the term in your specific context.<sup>42</sup>
- ⑦ In the methods section of a report or publication, explain how the researcher’s own social position could have influenced data analysis and/or interpretation of findings.

# Our Work is Relevant.

By providing actionable and timely analyses that lead to improved health equity, outcomes and value and are responsive to health priorities.



9

Scientists and project teams will address how **systemic racism** and discrimination experienced by certain communities could relate to their research findings. Steps for contextualization may include exploring systemic racism and discrimination related to the health system or broader influences on other social and structural determinants of health and indicating what additional steps may be needed to address health inequities.

10

When examining health differences by race or ethnicity, scientists and project teams should consider the interaction of important social determinants of health such as poverty and education, and the potential overlap of forms of discrimination such as racism, sexism and ableism.

## Example guidance for application

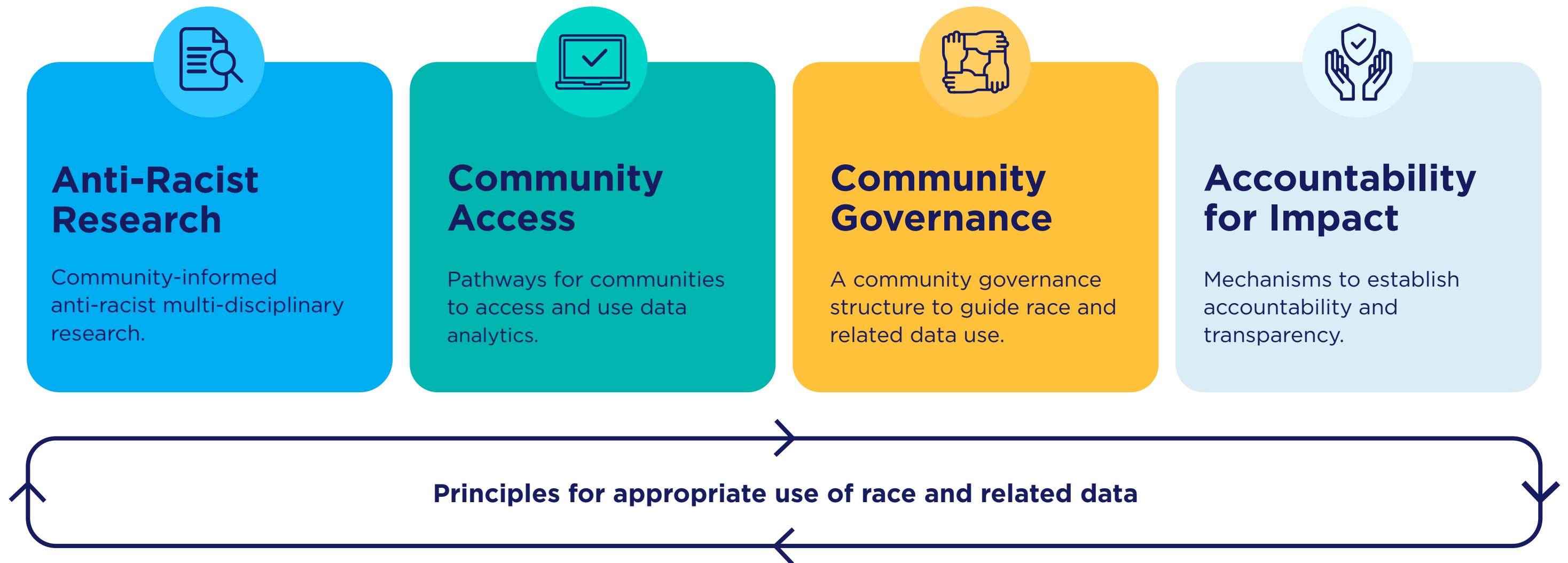
- ① Discuss in the interpretation how findings demonstrate the **intersectionality** of race and related constructs with other sociodemographic factors in the health context being studied. The role of **systemic racism** should also be overtly addressed, including a focus on potential solutions, rather than solely highlighting problems (i.e., avoid victim-blaming or emphasis on disparities).<sup>46</sup>
- ① Demonstrate in the implications section of a report or publication how the study will promote change or solutions specifically for the communities identified. This requires reflection on possible broader impacts of the work using a **health equity** lens and/or meaningful engagement with impacted communities.



# Framework to Drive Anti-Racist Approaches to Health Research at ICES<sup>†</sup>

The *Framework to Drive Anti-Racist Approaches to Health Research at ICES* (The Framework) is organized into four domains. Each domain includes a goal and components that guide ICES' commitment to racial equity in health research. At the foundation of the Framework are the principles for appropriate use of race and related data informed by the Peoples' Panel, a group of over 50 members of the public, which underpin the four core Framework domains.

The goals and components defined within the domains of the Framework represent a new vision for how ICES scientists can responsibly conduct research to advance health equity, by recognizing the experiences of racialized individuals, the uniqueness of race and related data and how these relate to health equity outcomes.



<sup>†</sup> The Framework to Drive Anti-Racist Approaches to Health Research at ICES was informed in part by the [ICES Indigenous Data Governance Principles Framework](#), which was developed in collaboration with the [Chiefs of Ontario](#) and the ICES Indigenous Portfolio. The ICES Indigenous Data Governance Principles Framework is a data stewardship model, where Indigenous data are held at ICES but governed by appropriate Indigenous organizations/communities.

DOMAIN 1

# Anti-Racist Research





## DOMAIN 1

# Anti-Racist Research

**Racism** continues to structure society and is perpetuated by harmful data interpretations, policies and legislation. Through the effects of racism, the **social construct** of **race** continues to have real and devastating consequences on health and access to healthcare. Race and related data can expose these inequities when used appropriately and with context and purpose, rather than for passive observation of difference. Dialogue on race must be repositioned away from biological or biomedical determinism and toward social and structural systems of privilege. Our consultations called for more guidance and tools to educate staff and scientists on the importance of exploring and understanding how measures of **race** and/or **ethnicity** intersect with other measures representing social determinants of health that shape health outcomes and health service utilization. When providing guidance and resources, it is also critical to distinguish between **race** and **ancestry**, as the latter can in some cases more accurately explain disease risks in certain populations. These changes align with many academic journals making a conscious shift toward more rigorous publishing standards and critically reviewing submitted research for appropriate use and acknowledgement of racism and racial disparities.

## Goal

Promote community-driven and community-informed anti-racist and multidisciplinary research at ICES.

## Components

- 1.1 Internal Capacity-Building and Community Engagement:** Providing education and resources on **health equity** and supporting meaningful community engagement with those who are directly impacted by the research.
- 1.2 Broadening Expertise:** Fostering interdisciplinary partnership and engagement with a broader community of experts in health equity research.
- 1.3 Data Quality Assessment and Data Acquisition:** Applying quality standards and controls to race and related data to prevent potential harm in the use and reporting of both existing data and data acquired in the future.





## 1.1 Internal Capacity-Building and Community Engagement

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As a research institute, ICES supports and enables investigator-driven research, as researchers' curiosity and insights can lead to important new discoveries and insights. Yet academic freedom must always be paired with the responsible conduct of research, especially the responsible use of race and related data. In addition to being necessary for research at ICES, it is also likely to improve a researcher's understanding of the meanings behind the data and help to ensure more relevant and impactful research is undertaken. ICES is well-situated to integrate additional resources and tools that underscore the importance of using race and related data responsibly and with a **health equity** lens. ICES scientists and project teams using race and related data should have adequate guidance how to do so in a thoughtful manner that minimizes harm and further stigmatization of certain groups. An organizational shift from passively documenting health inequities in research to centring community explanations and challenging systems and structures that are associated with those inequities requires adequate support. Therefore, resources on health equity and experiential knowledge from racialized groups (e.g., qualitative research), learning opportunities and one-on-one consultations with the Public Engagement and Knowledge Translation (PEKT) office will be made available to ICES staff and scientists. Internal capacity-building will be strongly encouraged with opportunities to attend relevant rounds, workshops and speaker series sessions. New ICES scientists, staff and trainees will be provided relevant information and resources during orientation.

ICES recognizes that building internal capacity among ICES scientists and staff to understand the history and complexities of race and related data is only one part of addressing **systemic racism**. Supporting community-informed research is also a key pillar of **anti-racist research**, and meaningful engagement with community stakeholders for projects using race and related data is strongly encouraged if appropriate and possible. The shift toward community engagement as an integral consideration for health equity projects will be initiated in phases as we evolve toward best practice and understanding what projects may benefit from this approach. As the organization works to create a repository of resources on meaningful community engagement for the ICES community, the PEKT office will also support scientists in planning and leading their own engagement efforts. When direct engagement with community stakeholders during the research project is not possible due to feasibility, study design or other constraints, scientists and project teams should have an established plan for how their findings will be disseminated directly back to community members whose data have been included.

## 1.2 Broadening Expertise

---

To further ensure sustainable efforts to build internal capacity and address a disciplinary gap in anti-racist research, ICES will create a strategy to broaden our expertise in health equity research and analysis through ongoing efforts to engage with a broad array of equity scholars across relevant disciplines. Outreach will occur to both established experts and scientists in training and will encourage opportunities for knowledge sharing. Initiatives will consider interdisciplinary collaboration on ICES projects through encouraging co-design and partnership opportunities. The goal of these partnerships is to foster internal and external capacity, increase institutional knowledge, increase visibility and awareness of ICES, create a network of stakeholders with equity expertise and support community engaged health equity research.

For non-ICES researchers accessing data through DAS, consistent and complementary policies for the use of race and ethnicity data will be needed. This Guidance Document and Framework should be shared with any non-ICES researcher in addition to the appropriate data holding obligations and manuscript requirements. For projects using race and related data with external partners, the project kick-off meeting should include discussion of how the data will be used, interpreted and disseminated appropriately and how to minimize harm. ICES staff working on the project team should reinforce these requirements at the time of publication when applicable. Project teams will also be encouraged to use the existing resources available at ICES on best practices for using race and related data. The same requirements listed above should also be enforced for project teams that include external collaborators working with ICES researchers on an ICES project.





### 1.3 Data Quality Assessment and Data Acquisition

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ICES will undertake a comprehensive assessment of the source and validity of its data holdings to scrutinize the quality of existing race-related data. These standards will also be applied to new race-related data prospectively considered for the ICES repository. An overview of the existing race-related variables and their source (e.g., self-reported on a survey, socially-assigned by clinician report, algorithmically-derived, etc.) can be found at the [following link](#) and will be updated annually. The gold standard source of race data is considered self-reported. However, limitations with the amount of self-report data available at ICES may result in the use of a proxy. Socially-assigned race may more directly lead to racial discrimination than how one self-identifies,<sup>36-38</sup> and therefore may be considered a proxy to use when studying the impacts of service providers' racial perceptions on patient treatment (for example).<sup>35,39</sup> This is of course assuming that service providers were sufficiently trained to consistently and honestly report perceived race for data collection.<sup>35,39</sup> Only in the absence of self-report and/or proxy data should an alternative (such as a validated algorithm that assigns race) be used.

ICES has a responsibility to create channels for race and related data for researchers with appropriate controls that ultimately ensure that communities under focus will be positively impacted by research. ICES will also continue to explore potential avenues of acquiring new data that is identified as a need by both scientists and communities to further enhance equity research. This will require comprehensive policies and procedures that foster reflection in scientists accessing administrative data or bringing in new data and the establishment of partnerships with community stakeholders to build awareness of ICES research and evidence as it becomes available.



DOMAIN 2

# Community Access





DOMAIN 2

# Community Access

Within the **data holdings** available at ICES, there are limited variables on race and related data and socioeconomic measures. Community organizations have been asking for data that are collected on their populations to be accessible. Having this data accessible helps to facilitate community-led research and analytics to improve services, advocate for resources and future funding and demonstrate systemic impacts of **racism** within the populations they serve. Equity groups and experts have also asserted the rights of communities to access their collective data and called on research institutes like ICES to expand their capacity to facilitate the use of these data by communities. While ICES has a funded mechanism called the Applied Health Research Question (AHRQ) program which enables health system stakeholders, referred to as “knowledge users,” to request data analytics to understand health services, its existence is not well known to community organizations. To improve community access to ICES data and analytics, awareness and capacity-building surrounding use of the AHRQ program for community organizations is critical.

## Goal

Create pathways for communities and organizations serving racialized communities to access and use data analytics through the AHRQ program.

## Components

- 2.1 Community Awareness and Accessibility: Building awareness of pathways to access and use race and related data analytics and ensuring these pathways are accessible to community organizations.
- 2.2 Mutual Capacity-Building: Supporting communities with the necessary context to use ICES data analytics and engaging in reciprocal learning from communities on the meaning of these analytics and their implications.



## 2.1 Community Awareness and Accessibility

---

Enhancing ICES' commitment to creating pathways for community access to data analytics and building capacity will require a comprehensive plan to increase awareness of these services. Information about the AHRQ program is currently outlined on ICES' website, but this may not be the first point of contact for communities without existing knowledge of the organization. Moving forward, ICES' efforts to increase awareness will include targeted mechanisms to establish engagement with stakeholders and organizations serving racialized and immigrant communities. These mechanisms to reach key stakeholders will be co-designed in collaboration with community organizations who have previously used ICES AHRQ services and key members of the public. Removing barriers to engagement and sharing information about what data are available and what questions can be answered using this data will be integral to a promotion plan.

Access to ICES' **data holdings** (repository) is well-established under the existing infrastructure of the AHRQ program to support communities in using administrative health data analytics for health equity research. However, as awareness of these services increases, ICES should consider acquiring additional financial support/funding pathways to support community-driven research questions and potentially develop an equity framework for resource allocation of new AHRQ projects. By eliminating barriers and making data analytics more accessible, communities will have greater control to drive **anti-racist research** and serve the needs of their population. Accessibility in the form of knowledge translation through transparency, open access or lay-language knowledge products of other community-driven research and ICES scientist-driven research on health equity must also be prioritized.

## 2.2 Mutual Capacity-Building

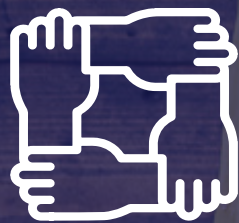
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The community of ICES scientists, staff and trainees has a diverse range of expertise in health research across the care continuum. Mentorship and capacity-building with community organizations looking to use their population data are already key components of accessing ICES data analytics through an AHRQ project. As awareness and demand increases for race and related data to address inequities across communities through the AHRQ program, resources and support will also be provided to contextualize the data and its source (e.g., self-reported survey data, socially-assigned by clinician report, algorithmically-derived, etc.). Knowledge users of community-driven AHRQs are the experts in the implications of their data and can reciprocally guide ICES in the analysis and contextualization of findings. The mutual capacity-building between ICES and knowledge users also supports development of clear and contextualized messaging delivered directly to communities that the knowledge users serve.



DOMAIN 3

# Community Governance





DOMAIN 3

# Community Governance

ICES' consultations have called for community-led governance as a key action for the appropriate use of race and related data to address **systemic racism**. The EGAP framework specifically proposed the establishment of a community governance table to build accountability of research institutions to communities. There are many existing models of community-led data governance, particularly from the foundational work that Indigenous organizations have led, that can serve as a guide to establishing structures for the appropriate collection, use and dissemination of race and related data at ICES. A community-led data governance structure must be co-designed by community members, organizations and key stakeholders, with the goal of establishing a clear mandate for the work and an advisory table. Like the Guidance Document itself, community-led data governance at ICES will be an evolving initiative as we continue to learn from community leaders and equity experts and work with stakeholder partners.

## Goal

Co-design and implement a community-led governance structure at ICES to guide corporate and project-level initiatives involving race and related data.

## Components

- 3.1 Community Governance Structure:** Co-designing a community governance structure and advisory table with community representatives.



### 3.1 Community Governance Structure

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ICES commits to establishing and co-designing a sustainable community governance structure with consultation from community representatives, stakeholders, experts and partners, including the MOH. Prior to implementation of a community governance structure, ICES will develop a comprehensive mandate that outlines the purpose; the boundaries and process of the work; what the community perspective will contribute; and transparency surrounding how the structure will inform corporate and project-level initiatives. ICES should develop the mandate and values in collaboration with community members to ensure that it reflects what matters most to racialized communities.

Establishing the governance structure, which will include a community governance advisory table, will follow once a clear mandate is established and agreed upon. To avoid duplication of efforts, ICES will also work with community partners and key stakeholders with existing structures and tables in place to learn from and potentially collaborate with on this process.

Communities will be engaged early in co-design, for both the mandate development and establishment of a governance structure, and ICES will put specific effort into understanding and conceptualizing diversity and representation to avoid homogenizing racial groups. ICES will consider the power differential between data professionals and community members and the power-shifting to community members that needs to happen through co-design, being mindful that trust must be built with communities and leaders within the community prior to starting this work. The community governance advisory table established under this structure will ultimately recommend where their expertise may be best leveraged. The governance advisory table's scope and role for corporate and project-level guidance will be clearly established through consultation with the table and other important stakeholders, such as the MOH.

**Although this guidance will be determined once the community governance advisory table is established, the following are examples of potential topics:**

- Suggestions for the acquisition of new data sources which contain race or related data
- Assessment of current data collection and data quality standards
- Revised standards for new data received by ICES
- Quality assessment of race and related data maintained within ICES
- Development or refinement of policies related to data access and use
- Review of partnerships with other data institutes using or leveraging these data
- Advise on the creation of infrastructure for community access and use
- Review ICES' benchmarks and metrics related to the goals of this Guidance Document

This domain component was informed by the insight of the aforementioned groups, as well as targeted consultations conducted in March 2023 with 13 community representatives and equity experts. These consultations provided detailed recommendations on how to plan for community-led governance of race and related data at ICES, which will be used to guide this work moving forward.



DOMAIN 4

# Accountability for Impact







## DOMAIN 4

# Accountability for Impact

Building capacity to appropriately use race and related data for health equity research can reveal systemic inequities and establish a research agenda geared toward solutions and change. However, inappropriate use of these data can instead perpetuate the status quo and cause further harm to communities. A concern raised by advocates and community groups is a lack of institutional accountability mechanisms for impacted communities. Our consultations with community members and equity experts emphasized the importance of establishing safeguards in the conduct of our research activities, demonstrating progress toward appropriate and equity-driven use of race and related data and adapting our processes when needed. To build more accountability to community organizations, the people whose data we are using and key stakeholders, ICES will develop reporting mechanisms and metrics to evaluate the implementation of key elements of this Guidance Document. These metrics will be continually evaluated and assessed to measure progress toward meeting the goals of the Guidance Document in the immediate and long term.

## Goal

Create and implement mechanisms to ensure accountability and transparency when using race and related data.

## Components

- 4.1 Knowledge Mobilization:** Providing research evidence directly to communities and creating opportunities for information sharing and mutual learning.
- 4.2 Transparency:** Creating an environment of transparency around research activities that involve race and related data.
- 4.3 Reporting Mechanisms:** Establishing comprehensive reporting mechanisms for community-driven research that maintains accountability and advances **health equity**.



#### 4.1 Knowledge Mobilization

---

ICES scientists using race and related data must be accountable to communities whose data they are analyzing and interpreting, and strategies are needed to ensure that such research is accessible to those directly impacted by the findings. This includes communicating evidence in plain language and ensuring key findings are directly accessible to partners and stakeholders who require this information for policy and practice changes. Once established, strategies to determine who should be informed of key findings will be determined in collaboration with the ICES community governance table and/or community partners identified by the project team. Scientists should also consider their own positions of privilege and the lens through which they interpret their findings. Community engagement and engagement with wider academic literature and equity researchers during these critical points in the research process should be well-established if appropriate. Broader knowledge translation and dissemination to the public should follow community-informed guidance on reporting of race-related findings and consider the larger impacts on health equity.

#### 4.2 Transparency

---

ICES is accountable to community partners, stakeholders and partners whose data are included in its repository. Over time, ICES has grown its intersectoral data partnerships and maintains accountability for data privacy and security, responsible use and disclosure and appropriate reporting and metrics. Therefore, transparency on research activities involving race and related data is paramount to these relationships and responsibilities. Research activities at ICES using race and related data should be monitored to provide transparency on progress toward meeting the committed actions of this Guidance Document and to tailor education and resources as needed. Mechanisms will be established to quantify metrics related to race and related data access and use at project initiation for controlled use data, and at the publication phase for all other data. Elements related to implementing the Guidance Document, including training and resources for scientists, will also be evaluated and updated accordingly.

#### 4.3 Reporting Mechanisms

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ICES is directly accountable to the MOH for the AHRQ program. However, there is an implicit accountability to the community organizations seeking data and analytic services to ensure practices and policies for data use are accessible and appropriate to their needs. Reporting mechanisms should be established for community organizations utilizing the AHRQ program to provide ongoing feedback on how the research process can be improved for accessibility and equity. Community partners, the MOH and other stakeholders should be engaged to help define what metrics would demonstrate progress toward increasing broader awareness of ICES and improved accessibility of data analytics. Pertinent targets and measures can be shared back to partners to provide visibility on progress toward community access of ICES data analytics using race and related data for community-driven projects.



## Implementation: Our Commitment to Action

We understand that a sincere commitment to equity, diversity and inclusion as part of advancing **health equity** research is imperative for the successful implementation of this Guidance Document and Framework, our longer-term goals of contributing to anti-racist science and motivating actions that reduce racial health inequities. Figure 1 below describes the committed actions that ICES recognizes as priorities in implementing this Guidance Document and Framework. These key actions have been recommended from consultations completed over the past 18 months with internal and external equity experts and members of the public. We believe that these actions as deliverables are paramount to achieving our goal of establishing an **anti-racist research** agenda at ICES focused on our vision of improved health and healthcare for everyone.

The committed actions follow many of our organizational research and administrative processes, with some infrastructure already in place that allows seamless integration of these pieces. Many of the actions are underway or completed, as seen in the “Work to Date” section (Figure 1). We realize that some proposed actions cannot be completed simultaneously and will require more time and resources for successful uptake. Other actions require more comprehensive efforts to be put forward in collaboration with data and funding partners. Therefore, as an organization, we commit to initiating actions by priority and actionability to maximize the opportunity for successful and efficient implementation across ICES.

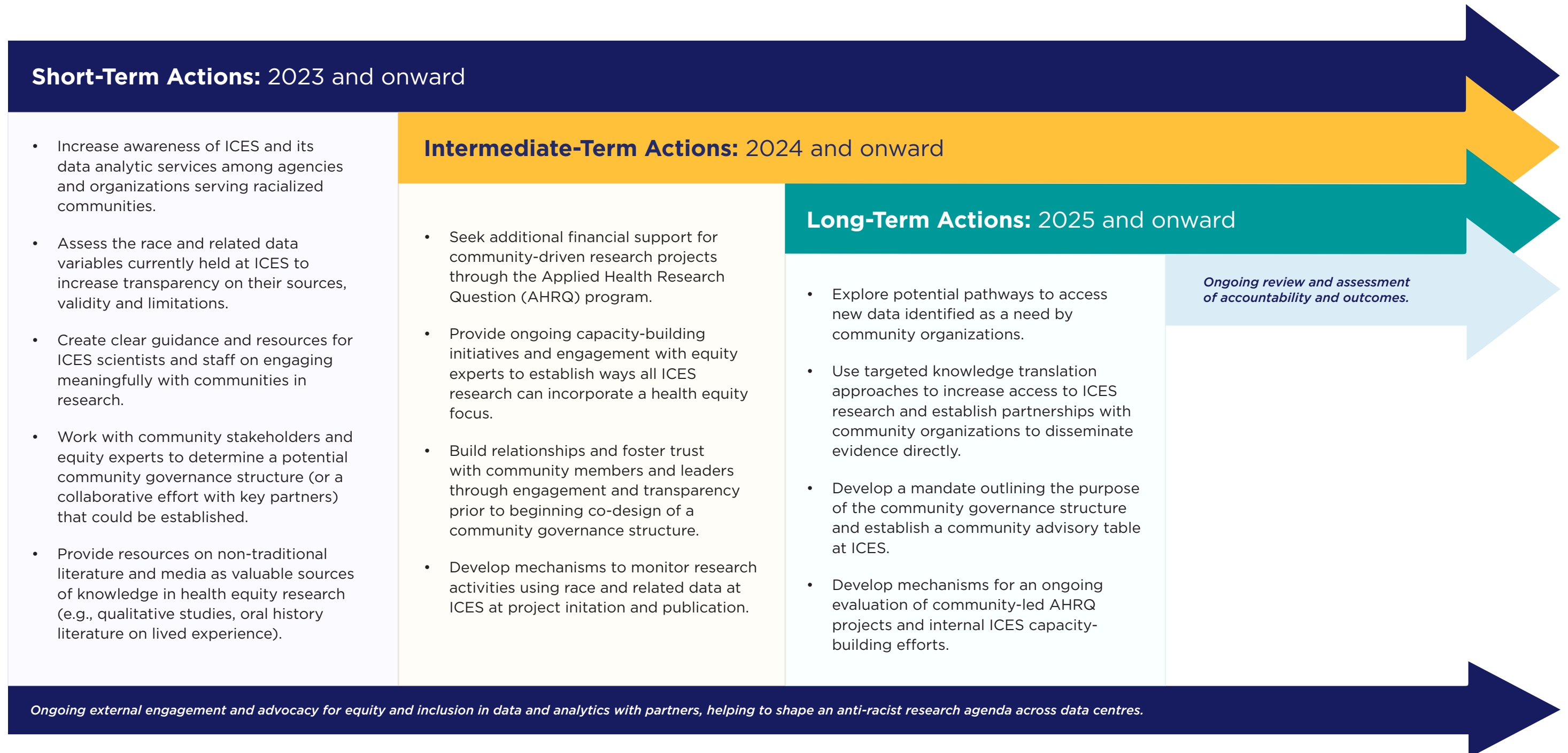
The actions listed under “Short-Term Actions” have been prioritized first, many of which are already underway. Actions under “Intermediate-Term Actions” will be launched in 2024, while “Long-Term Actions” will commence in 2025, as further resources or infrastructure are required to ensure successful implementation (Figure 1). We intend implementation to be iterative and adaptive. This Guidance Document is a living draft and will evolve as we consult with internal and external stakeholders. Yearly progress will be evaluated before the next implementation phase, including assessing accountability metrics and organizational outcomes.



Figure 1. Commitment to Action Timelines

## Work to Date: 2020 to 2022

- Consultations occurred with the public and key stakeholders including the Ministry of Health and health equity experts to establish priorities regarding how race and related data should be used and interpreted.
- Resources and rotating Speaker Series webinars were created to build capacity for ICES staff and scientists in health equity and anti-racist research practices.
- Guidelines were developed for conditional use of assigned-race variables and algorithms in the ICES data repository, and those that assign race based on country of origin and language alone were phased out.



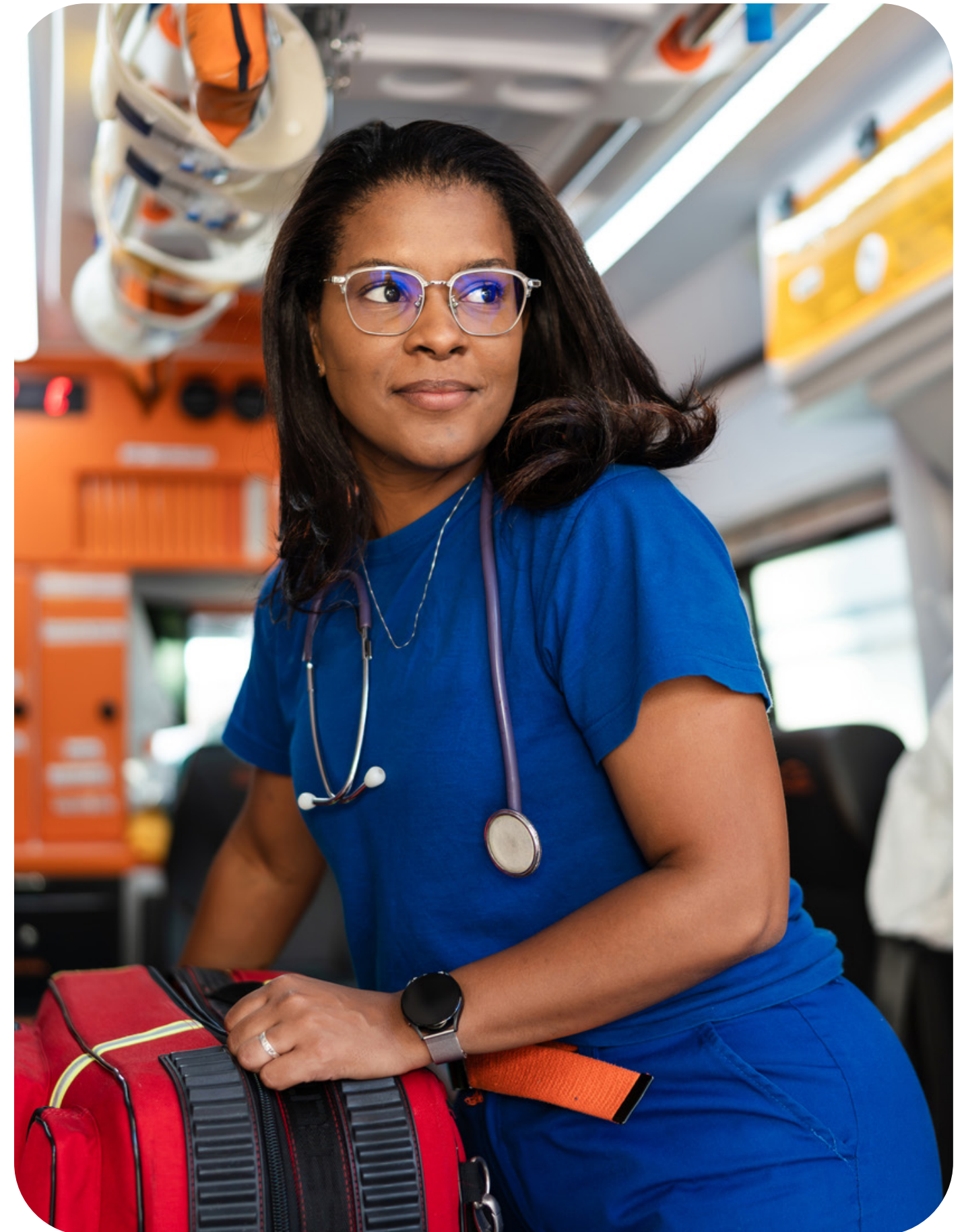


## Implementation: Practice Profile Methodology

This Guidance Document outlines ICES' priority of developing and sustaining appropriate use of **race and related data** in health research. We are committed to concrete approaches to **anti-racist research** and analytics at ICES that can be achieved over time through comprehensive implementation and evaluation planning. To successfully implement the key committed actions previously described and support the goals of this Guidance Document, a detailed plan is required to ensure consistency in what will be implemented across ICES, how, by whom and using what metrics for success.

The table below summarizes the key activities ICES will implement for each core component of the Guidance Document (Table 1). This template could be adapted to meet the specific needs of other data centres and research institutes interested in adopting a similar health equity research focus. The plan follows the Implementation Roadmap© Practice Profile Methodology, which deconstructs the core components of the Guidance Document.<sup>47,48</sup> In this instance, the core components are the practices and processes that must be undertaken to implement the Guidance Document's committed actions effectively. The Practice Profile Methodology also describes how each component will be delivered, who will be involved in the process and the key metrics required for evaluation.

Like the Guidance Document itself, this implementation plan is a living draft that will be continually updated and modified. Many of the activities required to achieve the core components will be community informed, and the below table is intended as a starting point for larger conversations and consultations. For more information on the details below or on how to implement a similar plan, contact us at [public@ices.on.ca](mailto:public@ices.on.ca).



**Table 1. Implementation Plan**

Core Components	Activities	Lead	Evaluation/Metrics
<p>1. Engagement with agencies and organizations serving racialized communities and the broader public</p>	<p><b>Explore</b></p> <ul style="list-style-type: none"> <li>• Engage in targeted outreach to agencies and organizations by:               <ul style="list-style-type: none"> <li>» Leveraging existing relationships with community partners to broaden networks</li> <li>» Establishing a relationship with new partners</li> <li>» Identifying and recording pathways/ process for community collaboration</li> </ul> </li> <li>• Conduct a needs assessment to understand resource preferences and methods for communication by communities</li> </ul> <p><b>Create</b></p> <p>Co-develop public-facing resources based on community needs</p> <p><b>Promote and Communicate</b></p> <ul style="list-style-type: none"> <li>• Develop and implement a communications plan that facilitates partner/stakeholder access to research findings and public-facing resources through:               <ul style="list-style-type: none"> <li>» E.g., Web/online modalities and voluntary email mailing lists</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Core Working Group</li> <li>• Public Engagement and Knowledge Translation (PEKT) Office</li> <li>• AHRQ Program</li> </ul>	<ul style="list-style-type: none"> <li>• Number of downloads of public-facing resources</li> <li>• Number of community-led AHRQ projects</li> <li>• Number of ICES research projects that engage with community organizations</li> <li>• Number of inquiries from the public and community organizations</li> <li>• Overall community organization network growth in the AHRQ program</li> </ul>
<p>2. Capacity-building opportunities and resources on health equity, experiential knowledge and community engagement in research for staff and scientists.</p>	<p><b>Explore</b></p> <ul style="list-style-type: none"> <li>• Conduct an internal needs assessment survey to understand training needs and resource preferences</li> <li>• Conduct an environmental scan of existing online resources</li> <li>• Evaluate existing resources for gaps</li> </ul> <p><b>Create</b></p> <ul style="list-style-type: none"> <li>• Create new, tailored resources/ training package to address gaps:               <ul style="list-style-type: none"> <li>» Training package to new staff</li> <li>» Host webinars and workshops</li> </ul> </li> </ul> <p><b>Promote and Communicate</b></p> <ul style="list-style-type: none"> <li>• Develop and implement a communications plan that increases awareness of new resources and tools</li> </ul>	<ul style="list-style-type: none"> <li>• Core Working Group</li> <li>• PEKT Office</li> <li>• Science Office</li> </ul>	<ul style="list-style-type: none"> <li>• Number of resources developed based on need</li> <li>• Number of downloads of internal resources</li> <li>• Number of attendees at webinars and workshops</li> <li>• Number of PEKT Office consultations on community engagement support</li> <li>• Percentage of staff and scientists who are satisfied with resources</li> </ul>

**Table 1. Implementation Plan**

Core Components	Activities	Lead	Evaluation/Metrics
<p>3. Resources to support community-led research.</p>	<p><b>Explore</b></p> <ul style="list-style-type: none"> <li>• Explore new funding opportunities or resources to support community-led research (e.g., letters of support)</li> <li>• Conduct a data needs assessment to understand additional data sources of interest</li> <li>• Explore new platforms to promote community-led projects</li> </ul> <p><b>Create</b></p> <ul style="list-style-type: none"> <li>• Develop a process to prioritize AHRQ projects with a health equity focus</li> <li>• Develop a report on funding opportunities, resources to support applications, platforms to promote community-led and equity focused projects</li> <li>• Where applicable, apply for funding</li> </ul> <p><b>Promote and Communicate</b></p> <ul style="list-style-type: none"> <li>• Develop and implement a communications plan that increases awareness of reports, new resources and tools</li> </ul>	<ul style="list-style-type: none"> <li>• Core Working Group</li> <li>• PEKT Office</li> <li>• AHRQ Program</li> <li>• Strategic Partnerships</li> </ul>	<ul style="list-style-type: none"> <li>• Number of AHRQs with a health equity focus</li> <li>• Number of ICES projects co-designed with community partners</li> </ul>
<p>4. Collaboration with equity scholars and scientists to broaden data science.</p>	<p><b>Explore</b></p> <ul style="list-style-type: none"> <li>• Engage in outreach with social scientist trainees to identify ways to collaborate and partner on ICES research</li> <li>• Engage in outreach to health equity scholars to identify ways to collaborate and partner on ICES research</li> <li>• Consult with equity scholars on existing ICES projects to identify gaps and opportunities for training and capacity- building</li> </ul> <p><b>Create</b></p> <ul style="list-style-type: none"> <li>• Establish new relationships with equity scholars to co-design ICES research</li> <li>• Create a report with recommendations, training plan and tools</li> </ul> <p><b>Promote and Communicate</b></p> <ul style="list-style-type: none"> <li>• Develop and implement a communications plan that increases awareness of reports, new training opportunities and tools</li> </ul>	<ul style="list-style-type: none"> <li>• Core Working Group</li> <li>• PEKT Office</li> <li>• Science Office</li> <li>• ICES Executives</li> </ul>	<ul style="list-style-type: none"> <li>• Number of new ICES scientists who are health equity scholars</li> <li>• Number of projects co-designed with health equity scholars</li> <li>• Overall ICES network growth with social scientists and equity scholars</li> </ul>

**Table 1. Implementation Plan**

Core Components	Activities	Lead	Evaluation/Metrics
<p>5. Organizational strategy for community data governance to guide the project and corporate-level decision-making.</p>	<p><b>Explore</b></p> <ul style="list-style-type: none"> <li>Conduct consultations with community organizations and community stakeholders on community governance and its potential co-design</li> <li>Review existing best practices in community governance and conduct an environmental scan for networks, partnerships and projects.</li> </ul> <p><b>Create and Consult</b></p> <ul style="list-style-type: none"> <li>Draft a report on the findings from initial community consultations and use findings to create recommendations for a governance model (either collaborative or independent) that includes a process for establishing a governance table</li> <li>Co-develop a clear mandate with community members that outlines the purpose of the governance structure, the boundaries and process of the work, where the community perspective will contribute and transparency surrounding how the structure will inform corporate and project-level initiatives</li> <li>Co-design a governance structure and form community governance advisory table with key community members and leaders</li> </ul> <p><b>Promote and Communicate</b></p> <ul style="list-style-type: none"> <li>Develop and implement a communications plan that increases awareness of the governance mandate, structure and advisory table</li> </ul>	<ul style="list-style-type: none"> <li>Core Working Group</li> <li>PEKT Office</li> <li>Science Office</li> <li>ICES Executives</li> <li>Community members</li> </ul>	<ul style="list-style-type: none"> <li>To be informed by the community governance advisory table</li> </ul>
<p>6. Mechanisms to monitor race and related data use and evaluate strategies to drive an anti-racist research agenda.</p>	<p><b>Explore</b></p> <ul style="list-style-type: none"> <li>Track race and related data use through Ministry submissions</li> <li>Track assigned-race algorithm use through data access request forms</li> <li>Evaluate the utility of internal educational tools and training</li> <li>Evaluate community satisfaction with the AHRQ program</li> </ul>	<ul style="list-style-type: none"> <li>Core Working Group</li> <li>PEKT Office</li> <li>Science Office</li> </ul>	<ul style="list-style-type: none"> <li>Number of publications using race and related data at ICES</li> <li>Number of publications taking anti-racist approaches (e.g., using community engagement, targeted community dissemination, etc.)</li> <li>Scientist satisfaction with ICES educational tools and training</li> <li>Additional metrics on community-led project satisfaction to be informed by community stakeholders</li> </ul>





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October 8, 2020

**Re: Race and Ethnicity Data at ICES**

ICES' vision is improved health and healthcare for everyone through world-leading research and analytics. As part of its commitment to trusted data stewardship, ICES is evaluating its approaches to data use and access to ensure that data are used in a respectful and appropriate manner to support healthcare for all. As the focus on the need for race and ethnicity data has increased in Ontario and more widely, the importance of collecting and using these data in a responsible manner has been highlighted by communities, human rights advocates and groups advocating for an anti-racist approach. As such, ICES is seeking to develop a framework to provide ICES scientists, trainees and staff with guidance on the appropriate use and governance of race and ethnicity data to ensure ethical and appropriate research and analytics. This framework will be designed with input from ICES scientists, staff, equity experts, community organizations and members of the public, specifically those representing racialized communities. ICES is also consulting with groups that have existing race data standards including the Ontario government, race equity groups and other research and data institutions. Please note that this framework will not examine Indigenous identity and data with Indigenous identifiers. ICES has a distinct approach and policies with respect to Indigenous data and works directly with Indigenous partners to ensure its use is appropriate.

In the interim, we request that ICES scientists and project teams using race and ethnicity data do so in a thoughtful manner that avoids harm and further stigmatization. We had initial consultations with members of the ICES Public Advisory Council who have shaped some of the following recommendations.

Project teams using race and/or ethnicity data should consider the following:

- Race is a **social construct**<sup>1</sup> and there is no universal measurement for it. Race is based primarily on observed physical traits such as skin colour and facial features. In almost all cases, higher risk/prevalence of adverse health outcomes should not be equated with biological or genetic predisposition<sup>2</sup> or used to demonstrate inferiorities of one or more racial groups.<sup>3</sup>
- Self-report is considered the gold standard for determining individuals' race and ethnicity.
- Those using the [ETHNIC dataset](#) to identify individuals who are South Asian and Chinese based on surnames should be aware of the misclassification bias given its positive predictive value (89% for South Asians, 92% for Chinese) and sensitivity values (50% for South Asians; 80% for Chinese). As articulated by its developers, exercise caution when using it to identify ethnicities of interest.<sup>4</sup>

- Those using the IRCC (CIC) data holding to assign race based on country of birth or country of birth + mother tongue<sup>5</sup> should be aware of the substantial misclassifications of some racial groupings due to assumptions within this algorithm, as well as the critical limitations (see below) with the validation approach; as a result we strongly discourage the use of this algorithm.
  - » Specifically, the Black race identifier is applied to any individual born in the Caribbean or Sub-Saharan Africa (South Africa was classified as White despite the fact there are Black South Africans in Ontario). This leads to substantial misclassification of people identified as Black. For example, according to the Statistics Canada census, while 90% of those immigrating to Canada from Jamaica identify as Black, just over 50% of immigrants from the rest of the Caribbean self-identify as Black, with the others identifying as South Asian, Chinese, mixed race, and other races.
  - » The algorithm also ignores important heterogeneity within racial groups.
  - » This algorithm was validated against 4 cycles of the Ontario portion of the Canadian Community Health Survey (CCHS). Of the 2.5 million immigrants in the IRCC dataset assigned race/ethnicity as above, only 6,499 immigrants were linked to the CCHS for the validation dataset (0.2% of the IRCC dataset). The authors acknowledge that this validation dataset may not be representative of the highly diverse immigrant population in Ontario.
- When using the IRCC (CIC) data, consider that reporting country of birth or citizenship may also potentially further stigmatize communities, and researchers should exercise caution to avoid perpetuating harm. Researchers should consider doing community engagement to better contextualize their findings in a respectful and honest way.
- When using the IRCC (CIC) data holding, include findings beyond the “immigrant/non-immigrant” classification to better contextualize the data.
  - » Incorporate information on immigration category (e.g. refugee, economic immigrant), socio-demographic (e.g. country of birth/origin, neighbourhood income), and other information (e.g. recency of landing, language).
  - » Consider labelling the “non-immigrant” category “Canadian born/long-term resident” as these data are only for immigrants and refugees who landed from 1985 onwards.
  - » The IRCC data only include those whose first place of landing in Canada was in Ontario and who became permanent residents. At this time, immigrants who landed in other provinces and then moved to Ontario will be in RPDB but their immigration status is unknown.
  - » Many temporary residents have access to OHIP but are not in the IRCC database (permanent residents only). New IRCC data feeds will include all Canadian data and temporary residents which will resolve these data gaps in the future.
  - » For a few example of ICES work which provide additional context to IRCC (CIC) data, see Banerjee & Shah (2020)<sup>6</sup>, the “COVID-19 in Immigrants, Refugees and Other Newcomers in Ontario” ICES report.<sup>7</sup>

<sup>1</sup> Williams DR, Lawrence JA, Davis BA. Racism and Health: Evidence and Needed Research. *Annu Rev Public Health*. 2019;40:105-125. doi:10.1146/annurev-publhealth-040218-043750

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Available: <https://www.ices.on.ca/-/media/Files/Atlases-Reports/2020/COVID-19-in-Immigrants-Refugees-and-Other-Newcomers-in-Ontario-Full-Report.ashx>





- When using the ON-MARG consider using the term “Ethnic Diversity” in place of “Ethnic Concentration” (apart from the technical explanation of the Index) and include all 5 quintiles of each measurement.
  - » This is not a measure of neighbourhood density but a proportion of individuals within a neighbourhood who are visible minorities and new immigrants.
- Incorporate data related to the social determinants of health alongside race, ethnicity, and immigration data to provide context around the role of systemic inequities and/or systemic racism.
- Meaningful engagement with members of the community who represent the races and ethnicities identified in your study cohort is strongly encouraged.<sup>8,9</sup>
  - » Community engagement strengthens the relevance of research to communities and the opportunities for research to be used for tangible community-driven improvements to health.
    - ◇ The ICES public engagement staff can provide supports and tools to assist with community engagement and are available for consultations.
  - » Community engagement can be time and resource intensive and as such it is helpful to consider it at the grant planning stage.
  - » Consider leveraging relationships and partnerships within ICES and your home institutions to identify community advisors.
- Seek opportunities to learn about and reflect on scientific/medical racism to avoid perpetuating harmful and scientifically inaccurate conceptions of race and/or ethnicity.

If you have any questions about the pending race and ethnicity framework or the suggestions above, feel free to reach out to us.

Sincerely,

**Astrid Guttmann**

Chief Science Officer

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Manager, Public Engagement and Knowledge Transition, Co-Chair Diversity Working Group

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**Sujitha Ratnasingham**

Director, Strategic Partnerships

## Appendix 2: Peoples’ Panel Report

In Spring 2021, ICES worked with the Tamarack Institute and Digital Justice Lab to lead a Peoples’ Panel composed of a diverse group of 54 members of the public to advise ICES on approaches to using race and related data for health research. Through this Peoples’ Panel, ICES sought to hear directly from members of the public, specifically those who identify as racialized, to understand their priorities and values for how these data are used and interpreted. We sincerely thank all members of the Peoples’ Panel for their contributions to the Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES.

**Download the Peoples’ Panel Report.**

**DOWNLOAD**

<sup>8</sup> Urquia ML, Moineddin R, Jha P, O’Campo P, McKenzie K, Glazier RH, Henry DA, Ray JG. Sex ratios at birth after induced abortion. CMAJ. 2016;188(9): E181-E190. doi: 10.1503/cmaj.151074

<sup>9</sup> Wanigaratne S, Uppal P, Bhangoo M, Januwalla A, Singal D, Urquia ML. Sex ratios at birth among second-generation mothers of South Asian ethnicity in Ontario, Canada: a retrospective population-based cohort study. J Epidemiol Community Health. 2018;72(11):1044-1051.



### Internal Teams

ICES has been on a journey to learn and reflect on the use of race, ethnicity and immigration data in its research. To conduct this work, ICES dedicated a Core Working Group responsible for developing and implementing a Guidance Document for Anti-Racist Approaches to Research and Analytics at ICES (formerly called “Framework”). The Document was established to guide the appropriate use of race and ethnicity data and a broader Internal Committee was also established to govern internal approaches for the access and use of race, ethnicity, and immigration data.

#### ICES Core Working Group

**Astrid Guttmann** (Co-Chair), Chief Science Officer

**Baiju Shah** (Co-Chair), Senior Core Scientist at ICES and SURNAMES dataset working group lead

**Laura Ferreira-Legere** (Co-Chair), Senior Manager, Public Engagement and Knowledge Translation

**Marian Vermeulen**, Senior Director, Research, Data and Financial Services

**Sujitha Ratnasingham**, Director, Strategic Partnerships

**Elise Leong-Sit**, Officer, Public Engagement and Knowledge Translation

**Susitha Wanigaratne**, Former Race and Ethnicity Data Advisor and Postdoctoral Fellow, ICES RESTACOMP Fellow, SickKids

**Jenine Paul**, Former Manager, Public Engagement and Knowledge Translation

**Bidjinie Coriolan**, Former Officer, Public Engagement and Knowledge Translation

#### ICES Internal Committee

The Internal committee consists of ICES researchers and research staff with expertise and/or responsibility related to racism, equity, and/or race and ethnicity data standards. Working with the core working group, this group provided input into the development of the GD and implementation plan.

#### **Aisha Lofters MD, PhD (ICES Adjunct Scientist)**

Family physician and research chair at Women’s College Hospital and ICES. Her research focuses on cancer screening and prevention with a health equity lens, particularly in Black women. She has published extensively on cancer screening inequities using immigration data at ICES.

#### **Fiona Kouyoumdjian MD, MPH, PhD, FCFP, FRCPC (ICES Adjunct Scientist)**

Family Physician, Public Health Physician and Epidemiologist, and Assistant Professor in the Department of Family Medicine at McMaster University. Her research is focused on the health status of people who experience incarceration, and she has recently been involved in research

and policy work focused on health equity including the use of data on race. She is also an Associate Chief Medical Officer of Health in the Ontario Ministry of Health and helping to lead the Ministry’s efforts around the collection and use of race variables.

#### **Husam Abdel-Qadir MD, PhD, FRCPC (ICES Adjunct Scientist)**

Cardiologist at Women’s College Hospital and the University health Network. His career in medicine was enabled by the Summer Mentorship Program and that continuously reminds him of the importance of initiatives to promote equity.

#### **Imaan Bayoumi MD, MSc, FCFP (ICES Fellow)**

Family physician and clinician researcher whose work is focused on social determinants of child health, including children and youth involved with the child welfare system. She partners with local Indigenous peoples in research, aiming to ensure Indigenous data governance.

#### **Lesley Plumtre PhD, MSc (ICES Staff Scientist)**

Staff Scientist for the AHRQ Portfolio in Data & Analytic Services (DAS) and member of the ICES Diversity Working Group. She holds a in Nutritional Sciences from the University of Toronto and a MSc in Nutrition from King’s College London.

#### **Patricia O’Campo PhD (ICES Adjunct Scientist)**

Executive Director of Li Ka Shing Knowledge Institute at St. Michael’s Hospital, Professor at the Dalla Lana School of Public Health and Canada Research Chair in Population Health Intervention Research, and member of Unity Health’s Council on Anti-Racism, Equity and Social Accountability. Her research focuses on health inequities by gender and race and calling attention to the prejudice existing in epidemiology. She is a leader in community participatory research.

#### **Refik Saskin MS (ICES Staff Scientist)**

Staff scientist with Data & Analytic Services (DAS) at ICES. His work focuses on facilitating research led by external investigators covering topics such as cancer, cardiovascular outcomes, drug therapy, healthcare utilization and costs, surgical complications and safety, and physician referral patterns.

#### **Susitha Wanigaratne PhD, MHSc (ICES Fellow)**

Social epidemiologist and Senior Research Associate at the Edwin S.H. Leong Centre for Healthy Children at the SickKids Research Institute. Her research considers immigration to be a structural and social determinant of health. She has published extensively using the immigration database at ICES and has experience with community-based participatory research methods.

**Former Internal Committee Members:**

Maria Chiu (Former ICES Staff Scientist)

- The Core Working Group is composed of leadership from key ICES departments including the Science Office, Indigenous Portfolio and Strategic Partnerships, Research and Data Analytic Services, and Public Engagement and Knowledge Translation. In Fall 2020, the Core Working Group developed a plan for the Document which was presented to the ICES Scientific Advisory Committee and have been working towards achieving the goals outlined in this plan.
- The group prepared a guiding Document outlining the goals, deliverables and activities that would take place as part of the Document and a memo that was shared with ICES scientists and staff with some interim guidance for using race data. This memo included some of the key best practices found from the literature review, considerations for using the immigration database, and two algorithms used at ICES that assign race and ethnicity variables. The Core Working Group convened a Peoples' Panel, which consisted of 54 public members, with specific representation from racialized individuals, to discuss what matters most to them about access and use of race data.
- The Core Working Group convened an Internal Committee composed of ICES scientists and staff with expertise or responsibility related to racism, health equity and race data. This committee has been tasked with providing advice and recommendations to the Core Working Group for the development of the guidance Document and producing the deliverables outlined in the guiding Document. The Internal Committee meetings began in December 2020 and occur bimonthly.
- The Internal Committee revisited the Document goals and discussed what deliverables to prioritize. They then reviewed existing best practices or emerging statements, guidance and frameworks related to race data use and discussed the emerging principles that the Core Working Group extracted from literature. They advised on potential steps that ICES could take to monitor the use of data that are not collected according to best practice, such as provider-assigned race data and algorithms assigning race data. The Internal Committee also reviewed and provided advice on how ICES should address the recommendations from the Peoples' Panel to guide ICES' use and governance of race, ethnicity, and immigration data both at the institutional level and at a research project level.

**Document implementation activities to date**

In advance of the formal launch of the Guidance Document, interim recommendations and learning opportunities related to race and ethnicity data and health equity capacity-building have been intermittently shared with ICES faculty and staff, including the following:

***ICES internal capacity-building***

The Core Working Group has laid the groundwork to support institutional change through comprehensive capacity-building strategies. There have been 3 pillars of work conducted to date:

- A resource page was developed for the internal ICES intranet that provides scientists and staff with information and interim recommendations on using race and related data in their projects. A bimonthly Health Equity in Focus reading list is also distributed in the recurring Science Office Newsletter as another means to provide staff and scientists with contemporary literature.
- A Health Equity in Focus speaker series was launched, which has so far included presentations from members of the People's Panel, representatives from Toronto Public Health, internal ICES speakers who have engaged with racialized communities as part of their research, and other external health equity experts.
- Support for scientists undertaking community engagement is also underway. A needs assessment was recently launched to determine what resources and supports are desired by the ICES community. The Public Engagement and Knowledge Translation Office at ICES will provide these resources as well as one-on-one consultations with scientists who would like more focused support on a community engagement plan for their research project.

### *Guidance on data holdings containing race and related variables*

- The Core Working Group had assessed an algorithm previously used in ICES research projects to assign race to individuals based on their country of origin and language using immigration data. The group received strong guidance that there are issues with any algorithm that assigns race based on categorization. Based on the concerns raised about the appropriateness and ethics of this algorithm, ICES phased out its use.
- Following this decision, a working group with subject matter expertise was established to develop a plan for another algorithm used to assign race variables. The assignment is based on surnames, and results were validated against self-reported census data. To ensure appropriate use of this algorithm, the data will be changed to controlled use, where a researcher must complete a Data Access Request form prior to using the data that outlines the goal of their project, the required use of the data, and what plans are in place to engage the community to whom the research applies. Research teams must also make certain acknowledgements in any reports, manuscripts, or presentations resulting from these data: the data are proxy variables (not self-reported ethnicity data), cohorts identified are subsets of certain ethnic communities, and observations cannot be extrapolated to entire ethnic groups. In the analysis and interpretation of the data, research teams are also encouraged to avoid broad biological or cultural generalizations as explanations for observations; instead, researchers are prompted to consider social determinants of health, systemic/institutional racism, and intersections/interactions between associated disaggregated factors.
- In addition to the work conducted to date on data algorithms at ICES, an assessment of all existing race and ethnicity data variables at ICES was completed. Within the administrative databases held at ICES, it is important to note that there is limited data on race and race-related variables collected from healthcare services or surveys like the census or the Ontario Health Survey. This assessment aimed to better understand the variables that have keywords related to race/ethnicity and increase transparency surrounding their source, validity, and limitations to their use.

### *External collaboration*

- In addition to internal consultations and efforts, the Guidance Document development and implementation planning have involved ongoing collaborative discussions with external research organizations and partners, including the Health Data Research Network (Inclusion, Diversity, Equity and Accessibility team), the Canadian Institute for Health Information, the Manitoba Centre for Health Policy, members of the Ontario Black Health Equity Working Group, and the Ontario Ministry of Health. These ongoing engagements have allowed the ICES community to learn from the work of others while also advocating for equity, inclusion, and an anti-racist research agenda with other data centres.

### **Next steps**

- A cornerstone of implementation is to support communities to drive their own research priorities, which ICES plans to achieve through improved community access to ICES data, meaningful community engagement, and governance guided by a model that will be developed in partnership with communities themselves. ICES will engage in more extensive dialogues with community organizations that serve racialized communities to gain further input on pathways to better facilitate community access to data through the Applied Health Research Question (AHRQ) program. Consultations will also be used to understand how to support communities using ICES data analytics to drive impactful and beneficial research.





The table below provides a list of key concepts and definitions used throughout this Document. Although not exhaustive, this list encompasses important foundational concepts to understand related to health equity research. A comprehensive list of concepts and definitions is available from [The Ontario Anti-Racism Directorate, Data Standards for the Identification and Monitoring of Systemic Racism](#).

Concept	Definition	Source
<b>Ancestry</b>	In the biological and social sciences, race is a social construct, not a biological attribute. In contrast to “race,” “ancestry” emphasizes the geographical origins of one’s ancestors (parents, grandparents, and beyond). Unlike “race,” the concept of “ancestry” does not focus on the static categorization of humans into groups but rather on the process by which a person’s history unfolded.	Chou V. How Science and Genetics are Reshaping the Race Debate of the 21st Century. Science in the News, Harvard University. Published April 17, 2017. Accessed May 27, 2022. <a href="https://sitn.hms.harvard.edu/flash/2017/science-genetics-reshaping-race-debate-21st-century/">https://sitn.hms.harvard.edu/flash/2017/science-genetics-reshaping-race-debate-21st-century/</a>
<b>Anti-racist research</b>	Anti-racist research is not content with describing and understanding differences. Rather, it intends to understand, challenge, and change the values, beliefs, and actions that sustain systemic racism. Anti-racist research methodologies include critical ethnography, critical discourse analysis, critical narrative inquiry, and Indigenous research methodologies with attention to the relational aspects of research – that is doing research with, not on, communities and individuals.	Indigenous and Anti-Racist Research Methodologies. Qualitative Research Café, University of British Columbia Blogs. Published September 5, 2020. Accessed 2022. <a href="https://blogs.ubc.ca/qualresearch/indigenous-and-anti-Racist-methodologies/">https://blogs.ubc.ca/qualresearch/indigenous-and-anti-Racist-methodologies/</a>
<b>Colonialism</b>	Colonialism is the historical practice of European expansion into territories already inhabited by Indigenous peoples for the purposes of acquiring new lands and resources. This expansion is rooted in the violent suppression of Indigenous peoples’ governance, legal, social, and cultural structures.  Colonialism attempts to force Indigenous peoples to accept and integrate into institutions that are designed to force them to conform with the structures of the colonial state. “Colonialism remains an ongoing process, shaping both the structure and the quality of the relationship between settlers and Indigenous peoples.”	What We Have Learned: Principles of Truth and Reconciliation. The Truth and Reconciliation Commission of Canada. Published 2015. Accessed 2022. <a href="https://publications.gc.ca/collections/collection_2015/trc/IR4-6-2015-eng.pdf">https://publications.gc.ca/collections/collection_2015/trc/IR4-6-2015-eng.pdf</a>
<b>Community/Communities</b>	Throughout this Document, the terms “community” and “communities” are used to define populations of individuals who have historically been excluded from health research, stigmatized or harmed as a result of research findings, and denied access and control of their data. These communities represent many marginalized groups, and this term is not meant to relate to geographically defined areas.	
<b>Data (Data Holding)</b>	ICES data is an inventory of coded and linkable health data sets. It encompasses much of the publicly funded administrative health services records for the Ontario population eligible for universal health coverage since 1986 (almost 14 million people).  The term “race and related data” refers to any data held at ICES that can identify or infer race, including race, ethnicity, or mother tongue. Certain immigration variables are also included under this umbrella term (e.g., country of origin).	About ICES – Frequently Asked Questions. ICES. Accessed 2022. <a href="https://www.ices.on.ca/About-ICES/FAQs">https://www.ices.on.ca/About-ICES/FAQs</a>



Core Components	Activities	Lead
<b>Ethnicity</b>	A multi-dimensional concept referring to community belonging and a shared cultural group membership. It is related to socio-demographic characteristics such as language, religion, geographic origin, nationality, cultural traditions, ancestry, and migration history (among others).	Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada. Canadian Institute for Health Information. Published 2022. Accessed 2022. <a href="https://www.cihi.ca/sites/default/files/Document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf">https://www.cihi.ca/sites/default/files/Document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf</a>
<b>Eugenics</b>	Eugenics is a set of harmful beliefs and practices aimed at “improving” the human population through controlled breeding. It includes “negative” eugenics (discouraging or limiting the procreation of people considered to have undesirable characteristics and genes) and “positive” eugenics (encouraging the procreation of people considered to have desirable characteristics and genes). Although pseudoscience and often considered a thing of the past, eugenic methods have continued into the 21st century, including the coerced sterilization of Indigenous women in Canada.	de Bruin, Tabitha and Gerald Robertson. <a href="#">Eugenics in Canada</a> . The Canadian Encyclopedia, 07 June 2019, Historica Canada.
<b>Health Equity</b>	Health equity is created when individuals have a fair opportunity to reach their fullest health potential. Achieving health equity requires reducing avoidable differences that are unjust. Many causes of health inequities relate to social and environmental factors including income, social status, race, gender, education, and physical environment.	Health Equity. Public Health Ontario. Published 2022. Accessed 2022. <a href="https://www.publichealthontario.ca/en/health-topics/health-equity/">https://www.publichealthontario.ca/en/health-topics/health-equity/</a>
<b>Intersectionality</b>	<p>Intersectionality is the way in which people’s lives are shaped by their multiple and overlapping identities and social locations, which, can produce a unique and distinct experience for that individual or group (e.g., creating barriers, opportunities, and/or power imbalances).</p> <p>In the context of race, this means recognizing the ways in which people’s experiences of racism or privilege, including within any one group, may vary depending on the individual’s or group’s relationship to additional overlapping or intersecting social identities such as religion, ethnic origin, gender, age, ability, or immigration status. An intersectional analysis enables better understanding of the impacts of any one particular systemic barrier by considering how that barrier may be interacting with other related factors.</p>	Data standards for the Identification and Monitoring of Systemic Racism. Government of Ontario, Anti-Racism Directorate. Published April 13, 2022. Accessed May 25, 2022. <a href="https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary">https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary</a>
<b>Marginalization</b>	Marginalization is a long-term, structural process of systemic discrimination that creates a class of disadvantaged minorities. Marginalized groups become permanently confined to the fringes of society. Their status is perpetuated through various dimensions of exclusion, particularly in the labour market, from full and meaningful participation in society.	Data standards for the Identification and Monitoring of Systemic Racism. Government of Ontario, Anti-Racism Directorate. Published April 13, 2022. Accessed May 25, 2022. <a href="https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary">https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary</a>
<b>Oppression</b>	Oppression refers to the use of power (both intentionally and unintentionally) by one group to disempower, marginalize, or exert dominance over another group. Acts of oppression can become institutionalized or systemic, thus becoming hidden and seemingly ‘normal.’ They can also play out on interpersonal levels, influencing values, beliefs, and actions	Understanding oppression and privilege. Ontario Association of Children’s Aid Societies. Accessed 2022. <a href="https://oacas.libguides.com/equity-AOP/oppression">https://oacas.libguides.com/equity-AOP/oppression</a>



Core Components	Activities	Lead
<b>Race</b>	Race is a term used to classify people into groups based principally on physical traits (i.e., phenotypes) such as skin colour. Racial categories are not based on science or biology but on differences that society has created (i.e., “socially constructed”), with significant consequences for people’s lives. Racial categories may vary over time and place and can overlap with ethnic, cultural, or religious groupings.	Data standards for the Identification and Monitoring of Systemic Racism. Government of Ontario, Anti-Racism Directorate. Published April 13, 2022. Accessed May 25, 2022. <a href="https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary">https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary</a>
<b>Racialized</b>	Racialized persons and/or groups can have racial meanings attributed to them in ways that negatively impact their social, political, and economic life. This includes but is not necessarily limited to people classified as “visible minorities”.	Data standards for the Identification and Monitoring of Systemic Racism. Government of Ontario, Anti-Racism Directorate. Published April 13, 2022. Accessed May 25, 2022. <a href="https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary">https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary</a>
<b>Racism</b>	Racism includes ideas or practices that establish, maintain, or perpetuate the racial superiority or dominance of one group over another.	Data standards for the Identification and Monitoring of Systemic Racism. Government of Ontario, Anti-Racism Directorate. Published April 13, 2022. Accessed May 25, 2022. <a href="https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary">https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary</a>
<b>Social construct</b>	An idea that has been created and accepted by the people in a society and that is not an intrinsic property of a person or thing.	Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada. Canadian Institute for Health Information. Published 2022. Accessed 2022. <a href="https://www.cihi.ca/sites/default/files/Document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf">https://www.cihi.ca/sites/default/files/Document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf</a>
<b>Systemic racism</b>	Systemic racism consists of organizational culture, policies, directives, practices, or procedures that exclude, displace, marginalize, or create unfair barriers to access valuable benefits for some racialized groups. This is often the result of institutional biases in organizational culture, policies, directives, practices, and procedures that may appear neutral but have the effect of privileging some groups and disadvantaging others.	Data standards for the Identification and Monitoring of Systemic Racism. Government of Ontario, Anti-Racism Directorate. Published April 13, 2022. Accessed May 25, 2022. <a href="https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary">https://www.ontario.ca/Document/data-standards-identification-and-monitoring-systemic-racism/glossary</a>
<b>White supremacy</b>	A system that assumes that the practices of whiteness are the right way of organizing human life. It refers to the “presumed superiority of white racial identities in support of the cultural, political, and economic domination of non-white groups.” The term white supremacy is intentionally not capitalized in this Document due to its inflammatory nature and sociopolitical contexts. <sup>33</sup>	National Collaborating Centre for Determinants of Health. <a href="#">Let’s Talk: Racism and Health Equity</a> (Rev. ed.). Antigonish, NS: National Collaborating Centre for Determinants of Health, St. Francis Xavier University, 2018.





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